Literacy levels required to complete routinely used patient-reported outcome measures in rheumatology

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Key messages

1 Patient reported outcome measures (PROs) are used frequently in rheumatology patient management and research

2 Many PROs are written at reading levels too high to be understood by many patients

3 PROs should avoid using complicated words so patients can understand and provide valid responses

Abstract

Objectives: This paper assesses the reading levels required to complete patient reported outcome measures (PROs) commonly used in rheumatology clinical and research settings.

Methods: Ten PROs written in English were evaluated. Four reviewers critiqued each measure blindly using two standardized readability indexes and a final readability score for each PRO was agreed.

Results: Only six of the PROs met the recommended reading level for health education literature.

Conclusions: Many people completing PROs will not be able to understand what they are answering and will be unable to give an accurate perspective on their condition.

Key words: Patient reported outcome measures (PRO), Reading levels, Literacy,

FOG Index

Background

Patients' and health professionals' perspectives of disease and functional ability differ [1]. Patient reported outcome measures (PROs) have a clear place in establishing levels of patient discomfort and ability; engaging patients in self-management and have a role in clinical research studies. PROs are accepted predictors and indicators for functional disability in rheumatology [2] and are important in gaining patients' perspectives on the personal impact of their disease [3, 4]. 'The Outcome Measures in Rheumatology Steering Committee' [5] agree that self-reported outcome for various patient domains are to be included in research and the UK government has received recommendations to increase the use of PROs in documenting effectiveness of health services for long term conditions[6].

In order to effectively complete self-report measures patients need to be able to read and understand the questions asked. It is reported that 22% of people in the US and UK attain no higher than a reading age of 10 years [7] and UK literacy levels are generally below those of mainland Europe with 20% of adults estimated as being "functionally illiterate", rising to almost 40% in some areas [8]. In 2000, The Moser Report concluded that 15% of adults have low literacy, 5% have lower literacy and 4% have very low literacy [9]. Patients with low literacy skills tend to be less responsive and less likely to adopt effective self-management skills of long-term conditions [10]. In Rheumatology, patients with low literacy skills have the highest rates of morbidity [11] and more anxiety and depression than those with higher literacy levels [12]. Attention has, therefore recently been paid to establishing health information material that is accessible to patients, in order to mediate these outcomes. Many tools have been developed to assess the reading level of written materials [13]; however, readability encompasses both the skill of recognising words and interpreting or comprehending them in the context of the writing, making it a difficult concept to measure [14]. Two standardised instruments are more commonly used because of their simplicity and consistency [15]. They are the Gunning's Fog Index (FOG) [16] and the Simple Measure of Gobbledygook (SMOG) [17]. In order to be read and understood by the majority of patients reading levels of health literature should range from grade 5 - 9 (ages 10 -14 years) [14].

Research into patient health literacy has so far focused on information giving and patient education. There has been little research to the literacy levels required to complete PROs. Patients are encouraged to be active partners in their health care and to adopt a range of self-management behaviours throughout their care pathway [4, 18]. Patients who are effectively involved in self-management achieve better health outcomes compared to those who do not [19].. PROs are now commonly used in Rheumatology to assess outcomes that are important to the patient but not easily assessed by traditional measures.

The purpose of this investigation, therefore, was to assess whether PROs commonly used in Rheumatology clinical and research settings would be easily read and understandable to patients who are requested to complete them.

Methods

As a paper based,non-experimental, descriptive study ethical approval was not required for this study. Ten functional PROs.were assessed:The Health Assessment Questionnaire (HAQ); The Arthritis Impact Measurement Scale II (AIMS II); The Short Form 36 (SF36); the Rapid Assessment of Disease Activity Index (RADAI); McMaster and Toronto Arthritis Patient Preference Questionnaire (MACTAR); The Rheumatoid Arthritis Quality of Life (RAQoL); The EuroQol (EQ5D); The Oswestry Disability Index; The Roland-Morris Disability Questionnaire; The Short Musculoskeletal Functional Assessment (SMFA). These were chosen as a representative sample of measures that were freely available to clinicians and had appeared in rehabilitation research publications over the past 10 years. (See: Table 1)

Table 1. The Patient Reported Outcome Measures (PRO)

PROs	No. of Items	Type of Question	Citation
Euro Quality of Life Questionnaire (EQ-5D)	5	Likert scale for mobility, self-care, usual activities, pain/discomfort &	EuroQolGroup. EuroQol – a new facility for the measurement of health-related quality of life. EuroQol Group. Health Policy 1990; 16:199–208. EuroQol Group. *EuroQol EQ-5D user guide*. Rotterdam: Rotterdam Centre for Health Policy and Law, Erasmus University. 1996.

		anxiety/depression, + calibrated 100 point line for general health	Hurst NP, Kind P, Ruta D, Hunter M, Stubbings A. Measuring health related quality of life in rheumatoid arthritis. Validity responsiveness and reliability of EuroQol (EQ 5D) Br J Rheum 1997;36:551-9.
Oswestry Disability Index	10 sections	1 question per section. Tick sentence that best describes condition today.	Roland M, Fairbank J. The Roland-Morris Disability Questionnaire and the Oswestry Questionnaire. Spine 2000;24:3115-24.
Health Assessment Questionnaire (HAQ)	20	Physical Disability 4 point Likert scale grading independence of activity. Categorical Scale	Bruce B, Fries JF. The Stanford Health Assessment Questionnaire: A review of its history, issues, progress, and documentation. J Rheum 2003;30:167–78. Fries JF, Spitz PW, Young DY. The dimensions of health outcomes: the health assessment questionnaire, disability and pain scales. J Rheum 1982;9:789–93. Pincus T, Summey JA, Soraci SA Jr, Wallston KA, Hummon NP. Assessment of patient satisfaction in activities of daily living using a modified Stanford Health Assessment Questionnaire. Arthritis Rheum 1983;26:1346–53. Wolfe F, Michaud K, Pincus T. HAQ-II: Development and validation of a revised version of the Health Assessment Questionnaire (HAQ). Arth Rheum 2004;50:3296–305.
Roland-Morris Disability Questionnaire	24	Tick if appropriate to today's condition	Roland M, Morris R. A study of the natural history of back pain. Part I: Development of a reliable and sensitive measure of disability in low-back pain. Spine 1983;8:141–4. Roland M, Fairbank J. The Roland-Morris disability questionnaire and the Oswestry questionnaire. Spine 2000;24:3115-24.
The Short Form 36-Item Health Survey (SF-36)	36	Varying choice on Likert scales ranging from 3 to 6 choices	Brazier J, Roberts J, Deverill M. The estimation of a preference-based measure of health from the SF-36. J Health Econ 2002;21:271–92. Ware J. SF-36 Health Survey. Manual and Interpretation Guide. Nimrod Press. 1997. Ware J, Kosinski M, Turner-Bowker D, Gandek B. How to score Version Two of the SF-36 Health Survey (with a supplement documenting Version 1). Lincoln, RI, Quality Metric Inc. 2002.
Rheumatoid Arthritis Quality of Life Instrument (RAQoL)	30	Yes = 1 No = 0 responses	Marra CA, Woolcott JC, Kopec JA, Shojania K, Offer R, Brazier JE, Esdaile JM, Anis AH. A comparison of generic, indirect utility measures (the HUI2, HUI3, SF-6D, and the EQ- 5D) and disease-specific instruments (the RAQoL and the HAQ) in rheumatoid arthritis. Soc Sci Med 2005;60:1571–82. De Jong Z , Van Der Heijde D, Mckenna SP, Whalley D. The Reliability and Construct Validity of The RAQoL A Rheumatoid Arthritis. Specific

			Quality Of Life Instrument. Rheumatology 1997;36:878-83.
Rheumatoid Arthritis Disease Activity Index (RADAI)	5	10 point scale + grading & duration am stiffness, Global disease activity, Arth pain, Tender joints	Stucki G, Liang MH, Stucki S, Bruhlmann P, Michel BA. A self-administered rheumatoid arthritis disease activity index (RADAI) for epidemiological research. Psychometric properties and correlation with parameters of disease activity. Arth Rheum 1995;38:795–98.
McMaster & Toronto Arthritis Patient Preference Questionnaire (MACTAR)	14	Physical Disability Yes / No - Ranking	Tugwell P, Bombardier C, Buchanan WW, Goldsmith DH, Grace E, Hanna B. The MACTAR Patient Preference Disability Questionnaire – an individualized functional priority approach for assessing improvement in physical disability in clinical trials in rheumatoid arthritis. J Rheum 1987;14:446–51.
Arthritis Impact Measurement Scale 2 – Short Form (AIMS 2)	26	5 point Likert response	Meenan RF, Gertman PM, Mason JH. Measuring health status in arthritis. The arthritis impact measurement scales. Arth Rheum 1980;23:146–52. Meenan RF, Mason JH, Anderson JJ, Guccione AA, Kazis LE. AIMS2. The content and properties of a revised and expanded Arthritis Impact Measurement Scales Health Status Questionnaire. Arth Rheum 1992;35:1–10.
Short Musculo-skeletal Function Assessment (SMFA)	40	5 Point Likert response	Swiontkowski MF, Engelberg R, Martin D, Agel, J. Short Musculoskeletal Function Assessment Questionnaire: Validity, Reliability, and Responsiveness. J Bone & Jt Surg 1999;81:1245-60.

Two standardized readability indexes, The Gunning's Fog Index (FOG) [16] and the Simple Measure of Gobbledygook (SMOG) [17], were used to ascertain the readability of each of the PRO questionnaires. The first 100 words of each questionnaire were employed for the FOG analysis and 30 sentences were randomly selected in groups of 10 throughout each questionnaire for the SMOG analysis. Four researchers independently scored the PROs using the indices agreed final scores.

Results

Six PROs fell within the recommended reading level (grade 5-9) for health education literature (Range: grade 6-8 [FOG] and 7-9 [SMOG]). Four PROs required higher literacy levels (Range: 11-12 [FOG] and one a grade 11 [SMOG]) andexceeded the recommended reading level for health education literature (See: Table 2).

Table 2: FOG and SMOG grade levels for PROs

PROM's	Average sentence length	Percentage hard words	FOG grade	Reading age (years)	Hard words in section of 30 sentences	SMOG grade	Reading age (years)
EQ-5D	6.7	7.9	5.9 (6)	**11**	22	7.7 (8)	**13**
Oswestry	7.7	6	5.5 (6)	**11**	20	7.5 (8)	**13**
HAQ	6.3	7.9	5.7 (6)	**11**	36	9	**14**
Roland-Morris	14.7	2.9	7	***12***	14	6.7 (7)	***12***
SF-36	6.3	13	7.7 (8)	***13***	27	8.2 (8)	***13***
RAQoL	11.1	9	8	***13***	25	8	***13***
RADAI	12.6	13.9	10.6 (11)	**16**	14	6.7 (7)	**12**
MACTAR	10.1	17.8	11.2 (11)	**16**	29	8.4 (8)	**13**
AIMS	14.4	11.9	10.5 (11)	**16**	30	8.5 (9)	**14**
SMFA	17	12.7	11.9 (12)	**17**	66	11.1	**16**

Discussion

This report demonstrates that 22% of the UK population would not be able to complete any of the 10 rheumatology PROs reviewed [7]. All require at least a reading age of 11 years (grade 6) to be able to read and understand the questions and the more difficult PROs need people to have had 11-12 years of schooling (reading age 16-17).Previous recommendations have suggested that health education literature should be written at no higher level than grade 9 (reading age 14 years) [14]. Six of the PRO's complied with this recommendation in both FOG and SMOG formulae. These were EQ-5D Oswestry, HAQ, Roland Morris, SF 36 and the RAQoL. Four of the questionnaires required reading levels above the recommendation (FOG Index). These were RADAI, MACTAR, AIMS-2 and SMFA. The implications of this may be that, given these are self-completed questionnaires, patients might not fully understand some questions and may therefore be submitting inaccurate reports of their experiences. These PROs could be made more accessible if a health care professional was able to support the individual in completion, however this has cost and time implications. Additionally the presence of a health care professional may alter the responses given.

PROs are being used increasingly frequently to capture patients' health-related quality of life and condition specific concerns [4]. A patient has the ability to complete the PROs when and where it suits them and can take an unlimited amount of time consider each question thoughtfully. A circumspectly completed PROspotentially assists the clinicaldecision making between health care professional and the patient. Independent completion by the patient potentially saves consultation time. Additionally PROs can provide a record of changes in the patient's condition in order to monitor treatment effectiveness. However, inaccurate responses may have the reverse effect of providing an erroneous programme of management or suggest spurious treatment effects. The patient's ability to read and understand the questions is a fundamental consideration to promote accurate responses. There are various ways in which the readability of PROscan be improved, as recommended when writing health information leaflets. One method is to reduce the length of sentences so that the reader can remember the beginning of the sentence by the time they reach the end. Sentences of 10-12 words are recommended to promote easier reading. Generally

PROs benefit by having short sentences; this factor has reduced the overall readability index for many of the questionnaires assessed. Oftentimes the instructions include lengthy sentences and become difficult to read and comprehend e.g. SF36 “During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious?)” (34 words).

In an assessment of patient literacy levels using the Rapid Estimate of Adult Literacy Measure (REALM), Swearingen [20] found that: “words not read correctly by 10% or more of the patients, included *diagnosis* (14%), *osteoporosis* (17%), and *inflammatory* (10%), and on the A-REALM, *rheumatologist* (11%), *cartilage* (14%), and *symptom* (14%)”. With the exception of ‘symptom’, all these words would be considered ‘hard words’ by both the FOG and SMOG indices as they possess three or more syllables. They are also referred to as ‘medical jargon’; words not commonly found in vocabularies outside of the health care field. In our analysis we found an overuse of hard words of three or more syllables or jargon/technical expressions (See: Table 2). To maintain an acceptable level for easy reading a maximum of 6 hard/technical words per 100 is recommended. Only two of the questionnaires (Oswestry and Roland-Morris) complied with this recommendation when assessed using the FOG index. None complied when assessed using the SMOG index. In fact, all questionnaires were deemed to possess too many hard/technical words and the reason that they mostly came out with acceptable levels of readability was the short sentence length. Words such as ‘difficulty’ ‘limited’ ‘activities’ ‘physical’ ‘disability’ and ‘arthritis’ were prevalent words in the questionnaires; such words could be explained or replaced to facilitate understanding. The reason that the SMFA scored high on the FOG index is that it contained both long sentences and a high number of hard words. “These questions are about how much difficulty you may be having this week with your daily activities because of your injury or arthritis.” (23 words in sentence and 4 hard words of three or more syllables)

Conclusion

The emphasis of the study has been to explore the accessibility of PROs, they have a useful and valuable role to play in health care monitoring because they give voice to the patient experience and if used well encourage patient engagement with their care. They aim to

increase the efficiency of clinical decision making. However, one of the criticisms levelled at PROs is responses may be inaccurate. If they are well designed patients should not require additional support and interpretation from health care professionals in order to completed them. If PROs are to be reliably used they need to be understandable to the patient and capture the patient experience in a clear and straightforward manner. This can be achieved by producing PROs that have short sentences containing fewer words with medical terminology.

References

1. Nothnagl T, Andel I, Sautner J,. Leder S, Bogdan M, Maktari A, Rintelen B and Leeb BF. Improvement and deterioration of rheumatoid arthritis: the patient's perspective. Ann Rheum Dis 2005; 64(S111):182.
2. Sanderson T and Kirwan J. Patient-reported outcomes for arthritis: Time to focus on personal life impact measures? Arthritis Care & Research 2009; 61(1):1-3.
3. Hewlett S. Patients and clinicians have different perspectives on outcomes in arthritis. J Rheumatol 2003; 30(4):877-9.
4. Department of Health (2012) Quality, Innovation, Productivity and Prevention (QIPP) Available from www.dh.gov.uk/health/category/policy-areas/nhs/quality.
5. Kirwan JR, Newman S, Tugwell P and Wells GA. Patient perspective on outcomes in rheumatology – a position paper for OMERACT 9. J Rheumatol 2009; 36(9):2067-70.
6. Marshall S, Haywood K, and Fitzpatrick R. Patient involvement and collaboration in shared decision-making: a structured review to inform chronic disease management. Report from the Patient-reported Health Instruments Group to the Department of Health. 2005; National Centre for Health Outcomes.
7. Carey S, Low S, and Hansbro J. Adult Literacy in Britain. 1997; London: Office for National Statistics.
8. Health, Literacy, and Trust. Reading and Health 2009; Available from: http://www.literacytrust.org.uk/Database/health.html.
9. Moser C. A fresh start improving literacy and numeracy. 1999; Department for Employment and Education.
10. Schillinger D, Grumbach K, Piette J, *et al*. Association of health literacy with diabetes outcomes. J Am Med Assoc 2002; 288:475-82
11. Walker D, Adebajo P, Heslop J, *et al*. Patient education in rheumatoid arthritis: the effectiveness of the ARC booklet and the mind map. Rheumatology 2007; 46(10):1593-96.

12. Gordon MM, Hampson R, Capell HA and Madhok R . Illiteracy in rheumatoid arthritis patients as determined by the Rapid Estimate of Adult Literacy in Medicine (REALM) score. Rheumatology 2002; 41:750-4.
13. Wilson FL, Williams BN. Assessing the readability of skin care and pressure ulcer patient education materials. J WONC 2003; 30(4):224-230.
14. Chapman J and Langridge J. Physiotherapy Health Education Literature. Physiotherapy 1997; 83(8):406-12.
15. Luk A and Aslani P. Tools used to evaluate written medicine and health information. Document and user perspectives. Health Ed and Behaviour 2011; 38(4)389-403.
16. Gunning R. The Technique of Clear Writing. 1968; McGraw-Hill, New York, 29-39.
17. McLaughlin G. SMOG grading - a new readability formula. J of Reading 1969; 12(8):639-45.
18. NICE Rheumatoid Arthritis Clinical Guideline 79: National clinical guideline for management and treatment in adults 2009; Available from: http://www.nice.org.uk/nicemedia/pdf/CG79NICEGuideline.pdf
19. Bodenheimer T, Lorig K, Holman H and Grumbach K. Patient self-management of chronic disease in primary care. J Am Med Assoc 2002; 288(19):2469-75.
20. Swearingen CJ, McCollum LBA, Daltroy HMPH, *et al*. Screening for Low Literacy in a Rheumatology Setting: More Than 10% of Patients Cannot Read "Cartilage," "Diagnosis," "Rheumatologist," or "Symptom". J Clin Rheum 2010; 16(8)359-64.